

Barbara Roberts

HB 5326

Connecticut Public Health Committee

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Madam Chair Member of the Committees

I am Barbara Roberts, Oregon's Governor from 1991-95 and I was my state's governor at the time of the passage of Oregon's Death With Dignity Law on our statewide ballot in 1994. I publicly endorsed the measure as Governor and remain strongly supportive after all these years.

I am pleased to submit written testimony before your Joint Committees today. In April of 2013 I testified before the Vermont House Human Services Committee on its Death With Dignity Bill, which was signed into law on May 20, 2013.

I am here today to share my experience and Oregon's unique leadership experience with our landmark law and the benefits that have come to our state.

As you may know, Oregon's law has twice been on the ballot for the decision of our voters: the first time by initiative petition in 1994 and the second time by legislative referral. The 1994 petition measure passed by 51%. The legislature's identical referral measure in 1997, passed with the voters' reaffirmation of 60%.

Then, and now, Oregon's citizens have continued to send a strong message of support for our state's end-of-life law. And across America, on-going polling continually reinforces citizen expectations and wishes about personal end-of-life options.

But even more relevant to your work here at the Capitol and in Connecticut, more relevant than Oregon's two voter-approved ballot measures, Washington State's voter approval, passage of the Vermont Death with Dignity Act, and the national polling results, is the impact that Death With Dignity has had on end-of-life's issues in Oregon.

Let me share with you what happened in Oregon starting in 1994. First came the two heavily financed campaigns...television and radio ads, public debates, newspaper articles and editorials, mailings and speeches.

Oregon voters became the best informed Americans in the 50 states on the subjects of dying, pain medication, heroic medical procedures, advance directives, and Hospice care. Dying was discussed over dinner, in bowling alleys, at hair salons and barber shops in gyms, classrooms, and churches.

Once families had opened those discussions, they couldn't put the toothpaste back in the tube! Lawyers were suddenly drafting more wills, more medical directives, recording medical powers of attorney.

As Oregon families and patients gained greater understanding of medical matters, treatment choices, and end-of-life options, they soon had expanded expectations of their own medical providers. Far beyond, simply the new Death With Dignity law, end-of-life began to change in Oregon.

Hospice use increased notably. High quality Hospice care was soon available in every one of Oregon's 36 counties. Today Oregon has one of the highest rates of Hospice utilization in the nation. What a positive impact this support and care has had for patients and their loved ones. More citizens in Oregon die at home than die in hospitals. Truthfully, it is what most of us wish for.

Since our law passed, Oregon's much-needed pain medication for terminal patients has resulted in a vastly-improved pain management system across Oregon. This improved pain management is more realistic, more caring and in many cases, has increased use. It has allowed more quality time for patients and their families. It has even prevented a number of violent suicides when patients suffered from under-treated pain. "Kinder and gentler" accurately describe end-of-life in Oregon.

It has become clear in my state that what we can talk about we can make better. Oregon's law has brought us both the discussions and the improvements.

But, if I might, there is a short but important discussion point I would like to share with you.

In the exchanges we've heard on the Death With Dignity proposals in a number of settings, there is a phrase I've heard a number of times regarding citizens with disabilities. That phrase is "slippery slope."

This phrase has no place in the discussion of this legislation.

I have spent more than forty years as a disability-rights activist. My older son is autistic and my political fight in 1971 for his right to a public school education was my first entry into the political process. From citizen advocate to Governor, I have continued my strong commitment to members of the disability community.

I have also experienced the challenges of a husband who was confined to a wheelchair for over seven years. At the time of my husband's death in 1993, Sen. Frank Roberts was the longest-serving member of the Oregon Legislature. He proved that his disability did not stand in the way of the remarkable contributions he made to public policy in Oregon.

So, let me state emphatically. I would never, never support a law that was harmful to individuals with disabilities.

And let me add, that in Oregon, after sixteen years of actual experience with this law, no person with a pre-existing disability has used the Oregon Law. The one possible exception is a person who was legally blind who had terminal cancer and she chose to use the Oregon law.

To raise the issue that Death With Dignity endangers those with disabilities has no basis in fact or in our

16 year experience. This argument is both baseless and unkind. It raises fears and anxiety in the disability community that, in my opinion, is a form of emotional abuse.

So, that said, let me take a short minute or two to lay out some real facts.

In Oregon, about 331,136 of our people die annually of all causes. In the 16 years from 1998 to 2013 approximately 498,179 Oregonians have died. In those same years, a total of 1,173 people have had prescriptions written under this law. 752 terminally ill patients have used the medications to end their lives. These numbers tell us two important things: (1) Oregon's Death With Dignity Law has been used sparingly and (2) every patient who has the prescription knows they retain the option for dying with or without the medication.

16 years. 498,179 Oregon deaths. 1,173 prescriptions written. 752 terminal patients choosing their own end-of-life path.

Predictions and campaign allegations of overuse and tragedy have been discredited. Oregonians have used the law sparingly and with full adherence to both the letter and the spirit with which the law was designed.

Oregon families have, over the years, shared beautiful and moving accounts of compassion, dignity, and gentle exits.

And again this past year of 2013 reflected many of the matters and facts we have found at year's end over the history of our law.

Year 2013 recorded 71 Deaths With Dignity: 69% were 65 years or older, 97% died at home, 65% had cancer, 86% were enrolled in Hospice, and 98% had some form of health care insurance. The deaths were 44 males and 27 females.

In the State of Washington, their four years of experience with the law have closely followed Oregon's. Their total numbers are a little higher- 104 deaths in 2012 (the 2013 results have not yet been reported) – but that likely reflects the larger population numbers in Washington State.

Oregon's law has been upheld through every state and federal court challenge all the way to the U.S. Supreme Court.

But the court of public opinion has been even more important for Oregon. The law has broad and deep political and public support.

Oregon is proud of the flawless way our law has worked in practice: Our state government's careful and detailed reporting system, the professional work and support of our medical and pharmaceutical communities, the strong partnership of Oregon Hospice, and an electorate that retains its protective support of the law.

I encourage your committee to bring that same positive outcome to the citizens of Connecticut. I fully trust that if you bring this caring option to your state, years from now you will look back on this decision

as I do today, with pride and gratitude for your state's leadership and compassion.